



This document is scheduled to be published in the Federal Register on 02/11/2016 and available online at <http://federalregister.gov/a/2016-02765>, and on [FDsys.gov](http://FDsys.gov)

DEPARTMENT OF HEALTH AND HUMAN SERVICES

Centers for Disease Control and Prevention

[30Day-16-15BHD]

Agency Forms Undergoing Paperwork Reduction Act Review

The Centers for Disease Control and Prevention (CDC) has submitted the following information collection request to the Office of Management and Budget (OMB) for review and approval in accordance with the Paperwork Reduction Act of 1995. The notice for the proposed information collection is published to obtain comments from the public and affected agencies.

Written comments and suggestions from the public and affected agencies concerning the proposed collection of information are encouraged. Your comments should address any of the following: (a) Evaluate whether the proposed collection of information is necessary for the proper performance of the functions of the agency, including whether the information will have practical utility; (b) Evaluate the accuracy of the agencies estimate of the burden of the proposed collection of information, including the validity of the methodology and assumptions used; (c) Enhance the quality, utility, and clarity of the information to be collected; (d) Minimize the burden of the collection of information on those who are to respond, including through the use of appropriate automated, electronic, mechanical, or other technological collection techniques or other forms of

information technology, e.g., permitting electronic submission of responses; and (e) Assess information collection costs.

To request additional information on the proposed project or to obtain a copy of the information collection plan and instruments, call (404) 639-7570 or send an email to [omb@cdc.gov](mailto:omb@cdc.gov). Direct written comments and/or suggestions regarding the items contained in this notice to the Attention: CDC Desk Officer, Office of Management and Budget, Washington, DC 20503 or by fax to (202) 395-5806. Written comments received within 30 days of this notice.

### **Proposed Project**

Congenital Heart Survey To Recognize Outcomes, Needs, and Well-being (CHSTRONG) - New - National Center on Birth Defects and Developmental Disabilities (NCBDDD), Centers for Disease Control and Prevention (CDC).

### **Background and Brief Description**

Congenital heart defects (CHDs) are the most common type of structural birth defects, affecting approximately 1 in 110 live-born children. According to previously published data, prior to the 1970s, many CHDs were considered fatal during infancy or childhood, but with tremendous advances in pediatric cardiology and cardiac surgery, at least 85% of patients now survive to adulthood. There are approximately 1.5 million adults with CHD in the United States today, and adults with CHD now outnumber children. With vast declines in mortality from pediatric heart disease over the past 30 years, it is vital to assess long term outcomes and quality of life issues.

For this one-year project, we will use data from U.S. state birth defect surveillance systems to identify a population-based sample of individuals 18 to 45 years of age born with CHD. We will then use state databases and online search engines to find current addresses for those individuals and mail surveys to them inquiring about their barriers to health care, quality of life, social and educational outcomes, and transition of care from childhood to adulthood. The information collected from this population-based survey will be used to inform current knowledge, allocate resources, develop services, and, ultimately, improve long-term health of adults born with CHD.

We estimate sending an introductory letter and survey to 6,675 individuals with CHD in the birth defects surveillance systems, and receiving completed surveys from 4,672 individuals (70%). The survey takes approximately 20 minutes to complete. The Contact Information Form will be provided in English and Spanish and should take approximately 2 minutes to read and complete. It is estimated that the total burden hours are 2,254.

There are no costs to participants other than their time.

Estimated Annualized Burden Hours

Type of Respondents	Form Name	No. of Respondents	No. Responses per Respondent	Average Burden per Response (in hours)

Individuals aged 18-45 years who were born with a congenital heart defect	Survey questionnaire	6,675	1	20/60
English-speaking mothers of respondents	Contact Information Form - English	757	1	2/60
Spanish - speaking mothers of respondents	Contact Information Form - Spanish	133	1	2/60

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[FR Doc. 2016-02765 Filed: 2/10/2016 8:45 am; Publication Date: 2/11/2016]